



Issue Brief: New Opportunities for Individuals with Disabilities to Expect Better Quality Services and Outcomes

The Home and Community-Based Settings Rule Attempts to Usher In Long Overdue Higher Standards

Introduction

For nearly 35 years, the federal Medicaid program has given states the opportunity to provide services and supports outside of institutions to individuals with disabilities who would otherwise be eligible for institutional care. Despite the fact that entitlement to institutional care remains a feature of the modern-day Medicaid program, many state Medicaid agencies have reached a point where they serve far more people with disabilities in non-institutional services (called “home and community services” or “HCBS”) than are served in institutional settings¹. Spending patterns have followed, despite the fact that the per-person cost of institutional care rises exponentially as states reduce the numbers of people served in these settings². There is irrefutable and long-standing evidence demonstrating that, on the whole, serving individuals with disabilities in home and community based services and settings costs less than serving those same individuals in institutional settings.

While we know that most individuals with disabilities and those who care about them prefer services to be delivered in home and community-based settings, the development of this Medicaid-funded institutional alternative has not been without its problems. First, not all states have embraced this opportunity to serve people outside of institutions. Many research studies have shown the benefits for individuals with disabilities and cost savings for states, while federal law has also prohibited unnecessary segregation of individuals with disabilities in

¹ As of 2012, the UCP Case for Inclusion website reports that 89.3% of people with ID/DD served by states are served in Home and Community-Based Services (HCBS). See: <http://cfi2014.ucp.org/data/>

² As of 2012, the UCP Case for Inclusion website reports that 86.1% of spending on people with ID/DD is spending on non-institutional services. See: <http://cfi2014.ucp.org/data/>

institutions since the Americans with Disabilities Act passed in 1990. Unfortunately, home and community-based services continue to be optional for states to provide, and states that do establish these options are permitted to limit the programs and make otherwise eligible individuals wait for access to home and community-based services. As a result, some states still either rely heavily on institutional services or leave hundreds, sometimes thousands of individuals with disabilities waiting for home and community-based services.

For many years, disability advocates focused their energies on ending states' reliance on institutional settings and ending waiting lists for home and community-based services. Access to home and community-based services was, and to some extent still is, viewed as the Holy Grail for people with significant disabilities who need support to live, work and participate in the world like the rest of us. As we have gotten closer to achieving this Holy Grail in many (although certainly not all) states, expectations are changing. The disconnect between the intent and reality within home and community-based services is becoming more stark. The lines between institutional and non-institutional supports are increasingly blurring. As a result, the Centers for Medicare and Medicaid Services (CMS) began nearly five years ago to attempt to define acceptable settings where Medicaid home and community-based service funding should be used. After two public "Notices of Proposed Rule-Making" and receipt of more than 2,000 comments on the subject from external stakeholders around the country, CMS published its final rules outlining standards and expectations for home and community based service settings in January, 2014. These rules took effect March 17, 2014. States have five years to bring their HCBS programs for frail elders and people with disabilities into compliance with the new rules.

An Unprecedented Opportunity

The **transition-to-compliance** process that states are required to undertake represents an unprecedented opportunity for individuals with disabilities, their families and allies, to influence the way home and community-based services are provided – not just *where* they are provided but *how* they are provided, including what opportunities and experiences are consistently made available to individuals receiving the services. For the first time, federal regulations require states to seek and utilize public comments on their home and community-based services programs. This means that states must now make their applications to start, renew or change a Medicaid funded home and community-based services program, and their transition plans to come into compliance with the new home and community-based settings rule, available for public review before these are submitted to CMS for approval, and they will need to create a method for organizations, associations and individuals within the state to comment on each application and transition plan. Federal regulations now require states to review and incorporate public comment into the final applications and transition plans they

submit to CMS for approval. The applications, once approved, typically govern the state's operation of its home and community based services program for a period of five years.

Why the Rule Defining Acceptable Home and Community-Based Settings?

As HCBS programs have evolved across the country, the service options being paid for by these programs have come under criticism for not facilitating the primary goals of the programs: namely, true community inclusion, equality of opportunity, and participation in the mainstream of community life, including gainful employment in the mainstream workforce for people who are working-age. Unfortunately, many individuals with disabilities and their families have endured first-hand, or heard about, years or even decades-long waiting lists and institutional experiences. As a result, they are often relieved just to get enrollment in an HCBS program, and their expectations are not as high as they might otherwise be. Any service offered is likely viewed as something not to be turned down out of fear that no other options may be available. Consequently, service options that are immediately available and historically typical are the ones that many individuals with disabilities and their families come to expect and even sometimes ask for, generally out of a belief that there is probably nothing else available. Sometimes, case managers charged with writing service plans for people in HCBS programs tell individuals with disabilities and their families that the options are limited, and they recommend accepting the most common, readily available options simply because they are readily available. As a result, demand reflects supply, which only results in greater supply of what is traditionally available. The system struggles to innovate beyond the status quo. To a large extent, the "status quo" options are now coming under much greater scrutiny through CMS's new home and community-based settings rule.

How Did HCBS Programs Get Off-Track?

While HCBS programs in many states may have left behind some of the characteristics of institutional models, one fundamental principle appears to have been carried over across the country. In the development of HCBS programs nationally, and in the most prevalent service delivery models used, the presumption has been that home and community-based services, like institutional services, need to **substitute for** community. Here are a few examples of how this principle has been put into practice in HCBS programs:

- Instead of supporting individuals with disabilities rent housing from ordinary landlords, we have created housing rented to individuals with disabilities by their HCBS service providers.

- Instead of supporting individuals with disabilities to secure employment with ordinary businesses, we have funded HCBS service providers to employ people in separate business locations owned and operated by these service providers.
- Instead of supporting individuals with disabilities to use typical community venues and programs for activities in which they wish to participate, we have funded service providers to establish separate locations where these activities are provided just for individuals with disabilities. A few examples include:
 - Fitness rooms in separate day service facilities rather than supporting people to participate in the local Y, fitness club, or fitness classes held at a community venue.
 - Art rooms in separate day service facilities rather than supporting people to participate in local art opportunities available to other community members.
 - Bowling leagues established specifically for people with disabilities and held at times that other leagues are not scheduled, rather than supporting people to join existing bowling leagues.
- Instead of supporting individuals with disabilities to utilize public transportation or adopt other ways of travel typically used by people without disabilities living in the same area, we have funded HCBS service providers to purchase and operate separate transportation specifically for people with disabilities and specifically transporting people from their provider-owned homes to their jobs or daytime “activity programs” at provider-owned businesses or facilities.

In fact, as we examine the nature of home and community-based services at this time, we see the most common service models (to which most of HCBS funding is dedicated) are all based on an assumption that service providers will *substitute for* the community and will offer simulated community experiences that do not result in real community inclusion and involvement. Most notably, we routinely expect that service providers will be landlords and employers for the people they serve, rather than acting as facilitators and supporters of individuals with disabilities to rent from ordinary landlords and work for regular employers. While three or four decades ago, when we first began creating home and community-based services, this may have seemed like the only viable approach to deinstitutionalization; in retrospect, HCBS programs across the country have made this virtually their only approach. Consequently, we now see federal regulations, explicitly defining what HCBS programs are supposed to offer to people with disabilities, appearing over thirty years after the federal government created the Medicaid HCBS program.

Unfortunately, the greatest threat to positive progress that might otherwise result from these new regulations is the inertia within existing HCBS programs in our country. Inertia is indeed a fitting term, defined as the resistance of any physical object to any change in its state of

motion, including changes to its speed and direction. It is the tendency of objects to keep moving in a straight line at constant velocity. While our home and community-based services systems are not “physical objects,” they are certainly pre-established systems that are now expected to change, evolve or at minimum adjust to the expectations outlined in the new regulations. Yet inertia may cause many states, and the service providers they utilize, to focus on the smallest degree of change that can meet the requirements: a sideways move; a minor adjustment in course; a slight deviation from what has been standard practice up to this point, or even more concerning – a simple redefinition or relabeling of the status quo with no actual meaningful positive change that will benefit the people with disabilities served.

In the face of this reality, it seems critically important to define the policy and practice that should underpin HCBS programs in this country. Regardless of whether we “get there” through the implementation of the new HCBS regulations, it’s vitally important we know what “there” is supposed to look like so we can avoid repeating the past and letting HCBS continue to develop in ways that are fundamentally in contradiction with its purpose.

Vision Is Needed: Innovative Service Models that Avoid Substitution for Community Need to be Highlighted

Starting with the basic premise that home and community-based services must substitute for community in the lives of people with disabilities, we have created what we have today: segregation and separation in people’s home and community-based experiences which has led to isolation of people with disabilities receiving HCBS services, despite their geographic and physical proximity to a community, its businesses, resources and people. By using publicly funded HCBS supports to substitute for community, our country gets no closer to mainstream employers, community groups, churches and neighbors embracing people with disabilities; we simply continue to engage the wider community for charity, often in the form of contributions to service provider organizations so they can:

- Build, buy or renovate more buildings that ultimately separate people with disabilities from the rest of their communities;
- Open more separate “programs,” further increasing the likelihood that “the community” will rarely encounter or engage with people with disabilities in any meaningful and on-going way;
- Maintain separate employment situations which preclude the need for meaningful efforts to assist individuals with disabilities to join the mainstream workforce; and
- Expand separate transportation systems, which eliminate the need to make mainstream public and private transportation accessible and available to people with disabilities.

What results is a society where people with disabilities are among us but still largely invisible and distinctly separate from the rest of the community. The vast majority of community members notice people with disabilities; but they do not know them.

How Could HCBS Reform Create a New Reality?

Many of the answers to this profoundly important question are already in front of us. In every state, without exception, there are HCBS providers who are acting as *facilitators* of community rather than *substitutes* for community. These support providers are builders - not of buildings or programs or transportation fleets - but of relationships, community access and community involvement. They do not talk about whether a person with a disability is a 'good candidate' for a community connected life; they do not create alternative programs for those who aren't 'good candidates'. They focus all of their energy and expertise on facilitating community for everyone they serve.

These providers rely on the same HCBS funding streams and administrative structures as other providers, and while we can and should still do much to improve the extent to which the existing HCBS funding streams and administrative structures truly support providers who approach their work in this way, the reality is that *it can be done*. Systems have typically labeled these service models as follows:

- *Supported Living*
- *Supported Employment*
- *Integrated Community Supports*

More recently, some states have also adopted labels like "Community Connector," "Community Navigator" and "Community Access" for some service models that are exclusively focused on facilitating HCBS participants' access to and use of generic community resources rather than creating separate, disability-specific programs that substitute for community resources in the lives of people with disabilities.

A sample of the provider agencies doing this work was profiled in a recent article³ that demonstrated taking this approach is both possible and sustainable, while it does not end up costing more than the community substitution models that are most common today. Few

³ See http://spechome.sharevision.ca/OISD/ParticipantReadings/Agency_Transformation.pdf for article entitled "Some lessons concerning agency transformation toward personalized services" by Michael Kendrick published in the International Journal of Leadership in Public Services, Volume 5: Issue 1; March, 2009.

would argue that the greatest single reason for the perpetuation and continued expansion of community substitution models, other than inertia, is the presumption of those administering HCBS funding that community connection models will inevitably cost more than community substitution models. As a partial result of that widely held belief, despite research to the contrary, is the strong culture in the current system which continues to encourage individuals, families and guardians to want and expect service models that are focused on community substitution rather than community connection.

If HCBS reform is going to occur, the new, federal settings regulations will likely be one impetus. Another impetus is clearly the US Department of Justice and its recent clarification of requirements for compliance with the Americans with Disabilities Act and the Olmstead US Supreme Court decision.⁴ Perhaps the greatest impetus for states will likely be the fact that the system cannot financially sustain itself for much longer while demand from eligible individuals with disabilities continues to grow. Perhaps the number one reason for seeking and expecting HCBS models that are focused on connecting people to their communities, rather than creating separate programs that substitute for community, is that natural supports can be sustained and expanded when people are supported to access, use, and participate in their communities. Separate housing, separate employment, separate activity programs and separate transportation eliminate the possibility of natural supports in people's lives because people are surrounded only by paid staff and other recipients of these separate services. This is a profound reality that cannot be ignored.

For those administering public HCBS funding, the key question is this: *What do you want to buy – what is your best investment of limited public dollars?* Is it those services that leverage and maximize natural supports, supports from other generic community resources and programs, and other publicly funded systems? Or is it those services that envelop HCBS participants in HCBS services, creating no need for, and no pathway to, people utilizing and relying on other types of supports? When states recognize their best investment is HCBS models that promote community connections rather than create a substitute community experience for the individuals with disabilities served, they will begin to tackle the culture that so strongly encourages individuals, families and guardians to want and expect service models that are focused on community substitution. A critical first step in HCBS reform must be a redefinition and realignment of case management within HCBS programs, and a commitment to ensuring the ready availability of service models that focus on community connection rather than community substitution. While this is no small challenge for most states, it is increasingly becoming a lesser challenge than sustaining the status quo.

⁴ See http://www.ada.gov/olmstead/q&a_olmstead.htm for June, 2011 Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*

